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Gender and age significantly determine patient needs and treatment goals in psoriasis - a lesson for practice

Running head Gender and age-related patient needs in psoriasis care

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Abstract

Background

Though patient needs are key drivers of treatment decisions, they are rarely systematically investigated in routine care.

Objective

This study aimed at analysing needs and expectations from the patient perspective in the German and Swiss psoriasis registries PsoBest and SDNTT with respect to treatment choice, age and gender.

Methods

The German and Swiss psoriasis registries observe patients recruited at first-time use of systemic drugs. Within 10 years, clinical (Psoriasis Area Severity Index (PASI), Body Surface Area (BSA)) and patient-reported outcomes are documented, including the Dermatology Quality of Life Index (DLQI) and the Patient Benefit Index (PBI), characterizing patient needs for treatment. The analysis dataset includes n=4,894 patients from PsoBest and n=449 from SDNTT with mean follow-up time of 7.5 months.

Results

5,343 patients registered between 2008 and 2016 were included in the analyses (at baseline: 59.6 % male, mean age 47.6 years±14.5, PASI 14.2±9.7, BSA 22.7±19.7, DLQI 11.3±7.2).The most important patient needs were to *“get better skin quickly”* and to *“be healed of all skin defects”*.

Subgroup analyses by age revealed significant differences in needs, especially higher needs regarding social impairments in patients younger than 65 years.

Patients 65 years or older attributed more importance to sleep quality, less dependency on medical visits, fewer side effects and confidence in the therapy. Out of 25 items reflecting patient needs, 20 items were rated significantly more important by women than men, with the greatest differences regarding feeling of depression, sleep quality and everyday productivity. Divided by treatment, needs were rated differently, recommending individualized and targeted choice of therapy.

Conclusion

Age and gender stratify patient needs. Women showed higher expectations and rated specific needs in psoriasis treatment higher than men. Analyzing the patient needs on an individual level will facilitate shared decisions by patient and physician in finding the optimal personalized treatment.

Keywords: patient needs, psoriasis, quality of life

Introduction

2.5 % of the German and Swiss population are affected by psoriasis[1]. This chronic disease can severely impact patient's quality of life[2], which can be improved greatly by new treatments.

Dermatologists' primary goal in treatment of psoriasis is objective improvement of extent of involvement. However, priorities differ between patients and physicians[3]. Psoriasis patients rate itching as much more bothersome than extent of involvement[3]. Patients' views and quality of life have increasing importance in the decision between different systemic treatment options. Hence, patient burden and needs are not sufficiently anticipated by the clinician[4]. This could be a reason why some patients with psoriasis feel misunderstood and not sufficiently perceived by their doctor as outlined in the Global Psoriasis Report (WHO 2016). This report concludes that a "patient-centered care" is needed, which implies shared decisions and substantial patient empowerment. The report also recommends to measure patient needs in a proper way and highlights the broad spectrum of patient needs in psoriasis care[5,6].

The patient needs questionnaire (PNQ), which records the needs far beyond quality of life instruments like the Dermatology Life Quality Index (DLQI)[7-9] and which determines these needs in five dimensions, was used in this analyses.

Beside data on needs already published[6], only limited data is available about a big cohort and patient needs respective age, gender or treatment choice. The current study investigated this topic in to our knowledge largest prospective psoriasis cohorts in two European countries.

Methods

Patient population and data collection

Adult patients with moderate to severe psoriasis who started systemic anti-psoriatic treatment were prospectively included in the national psoriasis registries of Germany (PsoBest) and Switzerland (Swiss Dermatology Network of Targeted Therapies (SDNTT)). In Germany, data was collected in 820 office-based dermatology practices and hospital-based outpatient clinics, in Switzerland by eight academic dermatology departments. The patients of the registry correspond to those in routine care and reflect real-life data[10]. The observation period runs up to 10 years. The patients have not previously been treated with inclusion treatment.

The two registries are registered with ClinicalTrials.gov (PsoBest: NCT01848028, SDNTT: NCT01706692). Before the start of the registries, ethical approval, if required for participating centers, was obtained. The registries suggest psoriasis treatment according to the European consensus paper on treatment goals in psoriasis[11] and the S3 guidelines for the treatment of psoriasis[12].

This analysis focused on the baseline data of all patients included between October 21, 2011 (SDNTT) or December 17, 2007 (PsoBest) until 31 December 2016, all having received one of the following therapies at the time of their inclusion: methotrexate, fumaric acid esters, ciclosporine, acitretin, apremilast, adalimumab, etanercept, infliximab, ustekinumab, secukinumab. The data acquisition was done according to the harmonized PsoNet study protocol, the international standards of epidemiological studies, requests of pharmacovigilance, and the German AWMF guidelines concerning the collection of life-quality data in dermatology[12]. CVderm

data management independently monitored and approved the data of all patient visits.

For analyses, patients were assigned to treatment groups based on therapy at inclusion.

Statistical analysis

Descriptive analyses were performed using standard parameters (absolute/ relative frequencies, means, SD). For comparisons, U-test, Chi-squared-test or Analysis of Variances (ANOVA) were used. Patients' needs were differentiated according to the specific treatment, patient age (< 65 years vs. ≥65 at baseline) and gender.

Assessments

Treatment needs and benefits were evaluated by using the PBI[13] subscales of the first part of the PBI, the Patient Needs Questionnaire (PNQ) at baseline (Table 1). Values between 0 (not important at all) and 4 (very important) are possible. Five PBI subscales are distinguished: 1 = reducing psychological impairments; 2 = reducing social impairments; 3 = reducing impairments due to therapy, 4 = reducing physical impairments; 5 = building confidence into therapy[8].

Results

Patients

Overall, 5,343 patients were included in the analysis (4,894 PsoBest and 449 SDNTT patients).

The majority of patients were male (59.6 %), the mean age was 47.6 years (Table 2). Patients had a mean weight of 85.5 kg (mean BMI 28.4) and 42.3 % were currently smoking (17.3 pack years on average). 37.6 % of the patients indicated that a first-degree relative was affected by psoriasis. The mean PASI was 14.2, the mean Body Surface Area (BSA) 22.7. Approximately every other patient had nail psoriasis (51.4 %, 6.6 nails involved on average), 19.1 % of patients had psoriatic arthritis.

Comparison of registries regarding baseline parameters revealed Swiss patients to be slightly younger (46.2 vs. 47.7 years, $p \leq 0.037$), lighter (83.4 vs. 85.7 kg, $p \leq 0.021$), and more predominantly male (65.9 % vs. 59.0 %, $p \leq 0.004$). As compared to PsoBest, SDNTT patients showed significantly lower disease severity (mean PASI 9.9 vs 14.6, mean BSA 14.0 vs. 23.5, both $p \leq 0.001$), but more SDNTT patients suffered from nail psoriasis (60.8 % vs. 50.6 %, $p \leq 0.001$) than PsoBest participants.

Patient needs

The most important reported patient needs were to *"get better skin quickly"* (94.0 % "quite/very important", mean PNQ score 3.7 +/- 0.7) and *"be healed of all skin defects"* 94.0 % "quite/very important", mean PNQ score 3.7 +/- 0.8) (Fig. 1). 92 % of all patients considered the parameters *"to have confidence in the therapy"* as well as *"regain control of the disease"* as important (both 92.0 % "quite/very important", mean PNQ score 3.6 +/- 0.9). Of lesser importance were social goals including *"to be less burdened in your partnership"* (57.7%, 2.3 +/- 1.7), *"to be less of a burden to relatives and friends"* (54.6 %, 2.3 +/- 1.7), *"to be able to have a normal sex life"* (54.0 %, 2.2 +/- 1.8) and *"to be able to have more contact with other people"* (52.0 %, 2.2 +/- 1.7). The least important item to our patients was *"be able to lead a normal working life"* (49.7 %, 2.0 +/- 1.8).

The seven need items rated highest by over 80 % of patients did not differ between treatment cohorts. However, other needs, i.e. those reported to be important by less than 70 % of patients, varied between treatment cohorts (Fig. 2). Especially the concern about side effects was reported at therapy start most frequently for apremilast (77.3 % "*quite/very important*") and ustekinumab (75.9 % "*quite/very important*"). In contrast, patients who started a treatment with fumaric acid esters indicated less fear about side effects to be one of their individual patient needs (61.0 % "*quite/very important*", Fig. 2). The registers did not indicate different profiles in patient needs between Germany and Switzerland.

Differences in treatment aims by age

Out of 25 PNQ items, 13 items were differentially rated in importance depending on age (Fig. 3). The younger patients (< 65 years of age at treatment start) rated the following aims at a higher level: *"to no longer have burning sensations on your skin"* (mean PNQ score 2.9 vs. 2.6, $p \leq 0.002$), *"to feel less depressed"* (2.4 vs. 2.2, $p \leq 0.029$), *"to be able to lead a normal working life"* (2.2 vs. 0.5, $p \leq 0.001$), *"to be comfortable showing yourself more in public"* (3.1 vs. 2.6, $p \leq 0.001$), *"to be less burdened in your partnership"* (2.4 vs. 2.0, $p \leq 0.001$), *"to be able to have a normal sex life"* (2.3 vs. 1.6, $p \leq 0.001$). Higher needs in older patients (≥65 years of age at treatment start) were found for: *"to be able to sleep better"* (2.2 vs. 2.1, $p \leq 0.024$), *"to be less dependent on doctor and clinic visits"* (3.2 vs. 3.1, $p \leq 0.001$), *"to have fewer side effects"* (2.9 vs. 2.8, $p \leq 0.031$) and *"to have confidence in the therapy"* (3.7 vs. 3.6, $p \leq 0.001$) highest.

Gender differences in treatment aims

Gender medicine has highlighted certain differences in diseases and treatment outcomes between women and men. We therefore evaluated differences in patient needs related to gender. Here, differences were even more distinct than those regarding patient age.

Out of the 25 items, there was a significant difference in 20 of them, all rated more important by women than men. Only, the aims: *"to be less of a burden to relatives and friends", "to be able to lead a normal working life", "to be able to have more contact with other people", "to be less burdened in your partnership",* and to *"to be able to have a normal sex life*" were not rated with significant differences between men and women (Fig. 4).

Discussion

Even though studies focusing on psoriasis treatment are abundant, they rarely investigate specific patient needs. Our study addressed this gap by systematically characterizing patient reported needs with respect to treatment based on prospective data collected in the German and Swiss psoriasis registries.

The dimensions of patient needs which were assessed independently from the treatment decision were shown to cover a wide range including social, physical, psychosocial burden, the desire to have confidence in therapy and impairment due to treatment (Table 1). The present data provide insights into individualized treatment goals and decisions. Differences found may come not unexpected to experienced clinical dermatologists. Our results indicate that women tend to suffer more intensely from this disease or at least stated higher treatment needs than men. This might possibly be driven by distinct aesthetic and social norms that women experience in our society[14,15]. We here have to point out, that the patient needs were assessed at treatment start and therefore are no result of treatment chosen but patient's expectation to treatment.

The complete dataset was stratified for gender and age to allow a more in-depth analysis of these subgroups.

Gender differences in treatment goals of psoriasis patients

Female psoriasis patients indicated to have overall higher expectations of therapy. Whether this is due to a higher subjective priority of women's appearance and ability to perform in daily life remains unclear. The items of the PNQ subscale social impairment were rated equally in 5 of 6 items by men and women, except of *"be comfortable showing yourself more in public",* which was more important to women. This indicates that appearance itself is more important to women. On the other hand, not only in this study both men and women stated great importance to the needs statement on social relationships, partnership and sex[16]. This indicates that the impact of the skin condition on relationships should be further explored. Psychological factors playing a role during exacerbation of psoriasis flares should be taken into diagnostic consideration[17]. Psoriasis patients report onset of lesions to be triggered by stress in more than 50%. Negative disease coping and suppression of

stress burdens influence psoriasis to an extend that flares occur more rapidly and severely. Finally, the association with alcohol and possible suicidal tendencies has been shown in several studies, especially for men[1,18].

Our results suggest that especially for female patients, strategies for individualized shared decisions are required to manage expectations correctly and to cope with disease burden. To our knowledge, this is the first analysis in a registry study comprising two countries that focus on this topic, which in the time of personalized medicine is rapidly gaining importance. Blome et al. did not find differences regarding age or gender when analysing treatment needs and their consistency over time[6]. However, there are some interesting gender differences regarding frequency of hospitalization[19]. There are higher hospitalization rates in men than in women.

Age differences in treatment goals

The sub-analysis of patient needs depending on age showed quite a few differences: For younger patients *"having a normal work life"* and *"having a normal sex life"* was significantly more important. This difference, as could have been expected, confirms that elderly patients have distinct needs from their younger counterparts.

In contrast, older patients attributed more importance than younger participants to specific needs like *"to be able to sleep better"*, *"to be less dependent on doctor and clinic visits"*, *"to have fewer side effects"* and *"to have confidence in the therapy"*. One reason for this might be that elderly patients more often have sleeping disorders and in general see their physician more often. Furthermore, being older, the psoriasis is expected to last longer and therefore overall more treatments have been unsatisfactory as confidence in therapy gains weight.

So far, the subject of patients' needs in psoriasis and their correlation with age has not been investigated sufficiently[6,20,21]. However, age-associated skin conditions and diseases were identified by the International League of Dermatological Societies, who found that the consequences of skin aging is one of the most important grand challenges in global skin health. Overall it is known that healthy skin during life course leads to better mental and emotional health, positive impact on social engagement, and healthier, more active, and productive lives[22].

Treatment goals

Overall, itching (or rather, the absence of it) was found to be a frequent treatment goal, which is in line with publications indicating the high prevalence of itch in psoriasis[23,24].

Moreover, *"getting a better skin quickly", "be healed of all skin defects", "be able to lead a normal daily life", "be comfortable showing yourself more in public"* are all related to having less disease visibility. In daily consultations, patients regularly express those needs[25,26].

According to our analysis, *"to have confidence in therapy"* was more important than *"having fewer side effects"*. This could suggest that people who are confident of a specific treatment and well informed about possible side effects tolerate those better.

Each patient has his individual profile of expectations and needs with regard to the desired treatment outcome and acceptable side effects *("have fewer side effects").* This profile is registered during the consultation and implicitly used to choose the best therapeutic option. In addition, the psychological precondition and impairment of quality of life of the patient might contribute to these needs. Formalised and validated methods are available for its characterization. The oldest as well as the simplest of these tools is the DLQI. However, it has the disadvantage of lacking robust scales for the dimensions of quality of life as well as the characteristics of the DLQI score as a sum score counting "*did not apply to me*" as score 0[7,8,27]. Newer tools, like the Patient Needs Questionnaire used in this study, are able to differentiate the patients' needs into 5 different dimensions, namely reducing psychological impairments, reducing social impairments, reducing impairments due to therapy, reducing physical impairments and building confidence into therapy[8]. They focus on needs rather on burden and thus facilitate communication related to treatment goals. We believe that the Patient Needs Questionnaire is hereby very helpful and more accurate than the DLQI when defining patients' needs. Accurate information concerning patients' needs can be helpful in selecting specific drugs that best fit the profile of the respective patient, thus resulting in a more personalized treatment approach.

„*To be free of pain*" was of greater importance in patients with psoriatic arthritis (PsA) and are in line with higher rated needs like "*to get better skin quickly*", *"be healed of all skin defects"*, *"to have confidence in the therapy"*, *"regain control of the disease"*, *"find a clear diagnosis and therapy", "be free of itching"*, *"have no fear that the disease will become worse"* among patients using drugs effective against arthritis. By

contrast, patients on fumaric acid esters, which are not effective in PsA, showed a very low needs score for pain reduction. Even though MTX is a first-line treatment in psoriasis arthritis, the need score for pain reduction is rated less in MTX-treated patients compared to the biologicals.

There were clear differences between groups regarding treatment choice in terms of needs for reduced side effects and tolerability. In particular, the association between lower patient need for side effects and fumaric acid ester treatment was striking in the light of subjective side effects and public safety discussions[28,29], it is not surprising that patients who started with fumaric acid ester treatment, rate the need for safe treatment at a lower level. However, the PBI was not explicitly used for such a selection. For this, the finding of specific patient needs profiles by drug rather reflect the results of obviously careful physician-patient interaction and patient-centred care. By contrast, patients starting a biological treatment all showed high expectations regarding the absence of side effects, which matches with the lower rate of intolerance and side effects associated with these drugs.

Analyzing patient needs with regard to disease course (*"have no fear that the disease will progress"),* we found that patients starting with apremilast rated the importance of this need lower than those receiving other drugs. We surmise that patients having a high level of fear of progression will be less willing to start a treatment with a considerable risk of failure such as apremilast, which is known to have a good tolerability and safety profile, but low efficacy[30].

We suggest that for treatment decisions, individual patient needs should be examined to identify and appropriately address patient-derived concerns. Some needs statements showed more distinct answer patterns than others, leading to a higher variance.

A better understanding of patient needs could help physicians achieve better therapy outcomes, higher patient satisfaction and quality of care[31,32]. Consequently, surrogate markers that reproducibly quantify patients' needs are gaining value. The more efficiently psoriasis patients' needs are addressed, the better the therapy adherence and ultimately the disease control. During the consultation, physicians need to assess the best individual treatment option based on the individual patient needs. We believe that the PBI questionnaire could be a helpful tool in this context.

In the future, the assessment of patient needs will allow to set specific individual treatment goals as well as projection and overall implementation of the patient benefit index. The questionnaire used in both registries allows patient-relevant needs and therapy benefit[7].

Taken together, analyzing the patient needs on an individual level will facilitate shared decisions by patient and physician in finding the optimal personalized treatment.

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Tables

Table 1 Patient needs questionnaire and its subscales

Reducing social impairments
• To be less of a burden to relatives and friends
• To be able to lead a normal working life
• To be able to have more contact with other people
• To dare to show oneself more
• To be less burdened in partnership
• To be able to have a normal sex life
Reducing psychological impairments
• To feel less depressed
• To gain in joy of living
• To be able to lead a normal everyday life
• To be more capable in daily life
• To be able to engage in normal leisure activities
Reducing impairments due to therapy
• To be less dependent on doctor and clinic visits
• To have to spend less time with daily care
• To have fewer out-of-pocket treatment costs
• To experience fewer side-effects
Reducing physical impairments
• To be free of pain

• To be free of itching
• To no longer have a burning sensation on the skin
• To be healed of all skin alterations
• To be able to sleep better
Having confidence in healing
• To have no fear that the disease will progress
• To find a clear diagnosis and therapy
• To have confidence in the therapy
Not attributed to subscales
• To regain control of the disease
• To get better skin quickly

Table 2 Patient characteristics

	N	Minimum	Maximum	Mean / %	SD
Age [y]	5345	18.0	92.0	47.6	14.5
Weight [kg]	5296	38.0	200.0	85.5	19.5
BMI [kg/m²]	5288	14.7	63.3	28.4	5.9
Gender (Female)	5346	.	.	40.4	.
PASI	5237	0.0	66.6	14.2	9.7
BSA	5238	0.0	100.0	22.7	19.7
DLQI	5070	0.0	30.0	11.3	7.2
Nail Psoriasis	5346	.	.	51.4	.
Psoriatic Arthritis	5346	.	.	19.1	.

*Missing data were not inputed, but total of available data is shown as collected

Figure Legends

Figure 1 Goals to reach for psoriasis patients sorted by overall importance and sub grouped by inclusion treatment (n = 5,343).

(ADA, adalimumab; ALL, overall treatments APR, apremilast; ETA, etanercept; FAE, fumaric acid esters; SEC, secukinumab; UST, ustekinumab; MTX, methotrexate)

Figure 2 Mean deviation from overall importance of treatment goals in psoriasis patients by inclusion treatment (n = 5,343).

(ADA, adalimumab; APR, apremilast; ETA, etanercept; FAE, fumaric acid esters; SEC, secukinumab; UST, ustekinumab; MTX, methotrexate)

Figure 3 Difference in patients need by age group (n = 5,343).

(* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$)

Figure 4 Differences in patient needs by gender (n = 5,343).

(* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$)